

## Zona and Ed Roberts: Twentieth Century Pioneers

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### Introduction

I earned a doctorate in history from the University of Oklahoma in 1981. Unsuccessful in my job search, I accepted a one-year instructorship at my alma mater. At the end of that year, my department chair inquired if I would be interested in writing a history for and about a private association located in another part of the state. I grabbed the opportunity. A number of phone conversations ensued. The association's representative encouraged me to submit a proposal and then helped me to refine it. During another phone call I was hired.

At my first in-person meeting with my contact, I walked into the airport terminal using a pair of crutches needed because of an almost lifelong disability. A written contract never materialized. Within a week I was informed that my use of crutches caused the association to determine that I did not possess the energy or stamina to do the job.

Angry and frustrated, I drove to the local center for independent living, a community advocacy organization for people with disabilities, which I had learned about from two students, to see what I might do to rectify the situation. To make a long story short, there was nothing I could do. Although everyone, from my colleagues to the Oklahoma Human Rights Commission agreed that I had encountered discrimination based on my disability, I had no legal protections.<sup>1</sup>

That summer I volunteered most of my time at the independent living center. In the fall I was hired to fill a new full-time position. Since 1982 I have worked in the disability rights movement, but I have never relinquished my academic roots. I continue to speak and to write about historical issues from a disability-rights perspective and disability rights from a historical perspective.

In 1990, shortly after chairing two panels focusing on disability history and culture, I accepted a training job at the World Institute on Disability (WID) in Oakland, California. I knew about, and held in awe, many of the exceptional people working at WID: Judy Heumann, first lady of the modern American disability rights movement, who had been a rebel since her New York City kindergarten had told her in the 1950s that she could not attend her neighborhood school because she used a wheelchair<sup>2</sup> and who, in the 1990s, was appointed by President Clinton to become an Assistant Secretary in the Department of Education; Simi Litvak, world-renowned expert in research about Personal Assistance Services, people aiding those of us with disabilities in tasks of daily living, such as getting in and out of bed, going to the bathroom, and getting to work; Deborah Kaplan, a disability rights lawyer, who had worked with Ralph Nader, and is a leader in innovations concerning technology and disability; Hale Zukas, seen by the outside world as a quadriplegic unable to speak intelligibly, who graduated with honors from the University of California at Berkeley with a double major in Russian and mathematics; and Ed Roberts, WID President, an internationally respected activist, considered equivalent in stature to Martin Luther King, Jr. by many in the disability rights movement.

I had not heard about Zona Roberts, Ed's mother. As I got to know both Ed and Zona I started to have a better grounding in the evolution of the disability rights movement. In December 1996, Zona visited our fairly new home in New Mexico to be interviewed at length for a project about Ed. At that time, I realized that Zona's tale was just as significant as that of her son.

A vibrant seventy-six year-old woman, whose age and gray hair belies boundless energy, Zona spent mornings ruminating thoughtfully for the tape recorder and afternoons touring southern New Mexico. When we came home, she wanted to go to the kitchen and cook, or play with our cats, before settling down for a quiet hour or two of reading.

When the interviews were completed, eleven hours of tape contained detailed, sometimes brutally honest, reflections about her life and times. I learned that Zona's life held fascinating detail before Ed's birth. She truly is a remarkable woman who is one of our century's pioneers and the

sharing of her story will, I hope, become part of our national lore.<sup>3</sup>

## Beginnings

Portland, Oregon, teenagers, Howard Harvey and Nada Post, met through a mutual love of music. Howard, the youngest of five children, possessed an ability to play a variety of musical instruments and did so at country dances. Nada, a carpenter's daughter, often sang at the dances. Nineteen year-old Howard and seventeen year-old Nada married and moved in with Howard's mother. Nada became a mother herself on April 1, 1920 when Zona Lee was born at the home of Nada's maternal grandparents, Elizabeth and Nelson Gilbreath. The birth apparently caused friction within the family because Nada's mother is rumored to have commented upon the birth, "you've had you're fun, now it's time to pay."

Following Zona's birth, the young family moved to Carver, Oregon where Howard labored in a lumber mill. Nada, an attractive woman with cultural ambitions centered around her love of music and art, found the extreme rural environment to be too isolating. She also had a lifelong fear, sometimes bordering on paranoia, about contagious diseases, including tuberculosis (TB), which was rampant in Howard's family. The couple separated when Zona was an infant.

Nada's fears were not entirely unfounded. Howard died from TB when Zona was about nine. The dissolution of this marriage might have been perceived as a portent. Howard and Nada's new-born daughter experienced a radically different childhood than we generally read about in the history books for middle-class America in the early twentieth century.

Zona's remembrances about her childhood with Nada focus on two aspects of life: the men in their lives and what each of them had to endure to survive. In her biological family, both Zona's maternal grandfather and great-grandfather were carpenters, but they played less significant roles in her childhood than the women of the matriarchal family. One of Zona's grandmothers married three times and Nada would eventually marry five times, four of those unions while Zona was still a child. Marriage was not a permanent event in the history of this family, with the exception of Zona's great-grandparents, Elizabeth and Nelson Gilbreath, whose lifelong commitment and love Zona desired to emulate.

After Howard's departure, Nada continued to seek the companionship and security she believed would result from marriage. She got a job at the Montgomery Ward store in Portland and while working there she met Leo Adams. When Zona was about four and too rambunctious for her great-grandmother to supervise comfortably Nada decided to marry Leo. She viewed him as quite a catch partly because he owned a home in Portland.

Zona remembers Leo as a jealous stepfather, who thought (mistakenly Zona believes) that he had married a little sexpot in Nada and that if Zona was not around life would be more exciting. Leo demonstrated his disappointment by becoming abusive. Zona recalls different incidents when her stepfather placed a pillow over her face and chased her with Halloween masks. During a trip to nearby Boise the family stopped at a dam and Leo held Zona over the edge. She bristles with rage even today recalling being sternly pinched her under the dinner table. Her stepfather terrified her and that contributed to the fairly rapid dissolution of this marriage.

Nada began working at a music school in Portland as a receptionist to help pay for singing lessons for herself and violin lessons for Zona. Teaching violin at the studio was Bob Barron, a music teacher, from Chicago, Illinois, who had been married before and was the father of two daughters.

Nada and Bob married. They left Portland when Barron obtained a summer job at the University the Pacific in Stockton, California. Zona was eight years old. The family then moved to the San Francisco Bay Area when Barron got a job at the College of San Mateo, south of San Francisco.

Barron, an only child, had been a violin protege, whose mother doted on him. He spent more money than he earned and he, too, had an unsavory side. It eventually became unclear if Barron had truly been divorced from his previous marriage when he met Nada. Complaints from students revealed he also was a child molester. In early adolescence, Zona, molested by a second stepfather, became depressed, complaining to her mother about Barron. Nada responded what would they do without him? A doctor suggested Zona needed a change of environment so she was sent to live for a

year with Nada's friend, Eleanora Peake, in Oregon. During this year, Zona told her cousin about Barron. The cousin informed her mother, Nada's sister, who then sent Nada a letter suggesting she look closer at her own home to discover what ailed Zona. When Zona returned to California for the summer, Nada asked Zona what the letter meant and Zona told her. Nada then sent Zona back to Oregon for a second year. She was a freshman in high school. During this time, Zona lived with cousins. These two years in Oregon's pastoral country setting freed her from the pressures of Nada's home and were two of the happiest and most serene of her childhood.

During Zona's second year sojourn in Oregon, Nada left Barron and had to get a job to support herself. An old Portland friend of hers owned a San Francisco dance studio and Nada began teaching ballroom dancing. She had been in poor health, but after starting this job she began to perk up, have fun and feel better. While there she met George Stephens (Steve), a student, and they soon became engaged. Zona learned about their impending marriage from the wedding announcement. Steve, who made a living in office management and bookkeeping, seemed to be able to satisfy and placate Nada and this, her fourth union, would be her only long-term marriage.

Steve's fascination with philosophy, including communism, and Eastern religions made him the first democrat with liberal ideas Zona ever met. This may have been true for Nada also. Some contemporaries perceived him as an early San Francisco radical. His interests in these arenas and in writing led Steve and a partner to try, unsuccessfully, to run a magazine. Perhaps Steve's worldly knowledge, immersion in a variety of activities, and kindly, unabusive nature, excited Nada enough to be satisfied in this marriage.

Nada returned to Portland shortly after she and Steve married because Zona, her cousin, Shirl, and her friend, Bye had run away for about four days. When they came back to the farm where Shirl's parents lived there was no one there as her mother, who had been experiencing quite a bit of pain, was in the hospital for a hysterectomy. The sheriff put the girls in jail for the weekend in Vancouver, Washington, until someone could come and take charge of them. Nada came up on Monday and Shirl and Zona went to the house where she was born - now her grandmother's house. Steve joined Nada soon after that and the newly wed couple stayed there for about a month.

Zona now obtained her first job doing housework for one of the English teachers at the high school in Portland where she hoped to finish her education after so many different schools in her young life. The house was a gray, dreary terrible place complete with a crazy sister who played harp. Zona was expected to do all the housecleaning and washing of the floors, but she had never been taught these activities. Nada visited after Zona had been at that place for about two weeks. She and Steve were leaving to go back to California. Zona responded by bursting into tears.

Shortly thereafter, Zona quit her domestic job and moved back to the house of her birth, with her grandmother. She stayed a brief time, then journeyed down to San Francisco to stay for a couple of weeks with in an apartment with Steve's parents. She enrolled at Galileo High in San Francisco, but realized she would prefer living down the Peninsula in Burlingame or San Mateo. She had visited Burlingame High School when Bob Barron conducted the orchestra at the College of San Mateo. Zona found a job with a family in Burlingame and worked her way through school for two and a half years, while living as a domestic with three different families.

While at Burlingame High School, Zona played in the orchestra and participated in drama. She wanted to participate in more extracurricular activities but had to work instead. Zona had also dated, but was most interested in survival.

While a senior in high school, Zona met Verne Roberts through a mutual friend. They first met to play tennis. The five feet eleven inch Verne later told Zona he liked her legs.

Verne, four years older than Zona, happily left high school to work when his father became ill during Verne's senior year. When he and Zona met he still lived with his parents in Burlingame, sleeping on a couch in the living room.

Zona graduated from high school in 1938. She also became pregnant that year while dating Verne. They visited an abortionist, but Zona refused to abort her baby. She and Verne married on July 4, 1938. Nada was not particularly happy with the marriage, believing Verne was not good enough for her daughter.

After their marriage, the newlyweds returned from their honeymoon in Fresno to San Mateo where they rented an apartment for a couple of months. Then Verne's parents bought them a four room house for \$2500 across from Burlingame High School and near their own home.

### Family Life

Verne's father, Walter, had worked for Southern Pacific Railroad as a machinist. Verne himself was on the Extra Board for the railroad, meaning that when there was work available he received calls to do odd jobs. Unfortunately, the jobs and the money evaporated during these Depression times. The couple applied for welfare. Verne applied for lots of jobs while waiting to hear about welfare. Zona remembers this as a horrifying experience. The morning the welfare worker was due to arrive, Verne got a job at a furniture store. He made \$25 week there before being called back to work at the railroad as an apprentice. Since he came in as Walter's son, railroad cohorts looked after him. He started as a machinist, then electrician, then diesel electrician. He rejected promotions to foreman, because he did not want the headaches of management, although he would sometimes fill the position on a temporary basis.

Edward Verne Roberts was born on January 29, 1939. Verne wanted to name a son, Ed, after his best friend. Zona preferred the name Michael, but Verne's parents, who had become very influential in her life, especially her mother-in-law, Catherine, who had accepted her into the Roberts family as one of their own, thought Michael was an Irish name and the Irish were denigrated in San Francisco.

Following a long labor, Ed was born, weighing a little over six pounds. Zona remembers looking at her child and thinking he looked like a monkey with dark hair. She remained in the hospital for about a week after Ed's birth. She recalls having a difficult time remaining still while in the maternity ward. She tried to nurse Ed, but had little success because of a tooth abscess that hemorrhaged. Ed was not getting enough nutrition. Once the problem was discovered, Ed received food supplements which alleviated the situation. The cost for pre-natal care, delivery, and post-natal care was \$50. When Verne and Zona brought Ed home they put him in a bassinet next to their bed and Zona said, "Well, here we are - I don't know how we're going to do it, but we're gonna do it!"<sup>14</sup>

Creating family stability to avoid repeating her own chaotic childhood became paramount. Zona recognized deficiencies in meeting this goal, such as her initial lack of cooking skill. At the beginning of her marriage her specialties were jello salads and cakes. Verne's mother always had a pot of soup going and Verne would frequently venture over there in the evenings.

Roberts' family gatherings, such as holiday celebrations, often happened at her in-laws house, which Zona enjoyed. After several years, Verne questioned why they always spent holidays at his parents' house. So during one mid-1940s Thanksgiving Zona cooked chicken and then the family ventured across the street to attend the big football game, San Mateo High School versus Burlingame High School.

Ed was an early walker and talker, saying "kitty-cat" when he was about nine months. He ran everywhere taking after his father who liked running so much that he once chased a dog around the block to get him back into the house. Ed constantly drove his top teeth through his bottom lip while scurrying around.

A day after her twenty-second birthday, April 2, 1942, Zona gave birth to the family's second son, Ron. He was a very blonde, gorgeous baby, similar to the Gerber baby. Ron tagged along with Ed when he went to the high school to play. One time Ron suffered a concussion when he was hit by a car while running after Ed. That was the first major trauma for either boy.

Ed began nursery school, then attended McKinley Elementary School. Still in constant motion, his motivation for going to school was the playground where he was the center of attention and activity. Ed did not sit still long enough to learn to read until the fifth grade.

Verne, fitting the middle-class stereotype of the day, spent much of his time at home in the garage fixing things or gardening. He was well-known throughout the neighborhood as someone who could and would lend a helping hand. He knew more about their neighbors than Zona did. Verne

wanted Zona to be at home as well perceiving a homemaker as someone who literally remained in the home. Most of Zona's friends, also married to blue-collar workers, had similar constraints.

Despite Verne's preference, Zona managed to find many opportunities to become involved in her community. She would strategize ways to leave the house. Some of these activities played formative roles in her later life and career choices. For example, she volunteered for the McKinley School Parent Teacher Association (PTA) whose activities included sponsorship of a sex education film from Oregon that had been developed for parents and children, and she later became PTA President.

Their third son, Mark, was born when Ed was about twelve and Ron about nine. When Mark was about two months old, Zona and her friend Marge Katzen applied to be census takers. Zona took the exam and got the job, but Marge was denied because she was Canadian, so while Zona went out, Marge took care of Mark and they then split the money. This emphasis on friendship and sharing remained a consistent pattern throughout Zona's life.

The couple's fourth, and final child, another son, Randy, was born about two and half years after Mark.

## Polio

Life changed dramatically for the Roberts family in early 1953. Ed returned from a March of Dimes benefit baseball game saying he did not feel well. He planned to go out again that evening, but Zona refused to let him leave. That night, Ed came into his parents' bedroom and slept stretched out between their two beds.

The next morning Ed awoke with a fever, stiff, holding his spine very straight. A doctor came at dinnertime, looked at Ed, washed his hands, and immediately wanted to take Ed to San Mateo County Hospital. The physician believed Ed could have flu, meningitis, or polio.

Ed walked into the hospital. The doctor performed a spinal tap to detect meningitis. Ed got up once during his first evening in the hospital to go to the bathroom; two days later he was rushed into an iron lung when paralysis began and included his neck and lungs.

When Ed contracted the polio virus, the family had known only one other person who had polio and who had died as a result. They were petrified about what would happen to their son.

At the hospital, they could only visit Ed through the windows of his room. Ed's fever escalated at the end of the week, creating a life-threatening crisis. Verne and Zona stayed at the hospital on Friday evening watching to see if a tracheotomy would be needed. Zona also feared that her mother-in-law would call for a priest did not want Ed to be alone if that happened. Ed awoke that night at about 2:30 a.m. He could not see parents from his solitary bed inside the isolation ward, but he knew they were still there. He projected his voice loud enough that they could hear Ed asking why they were still there. Verne and Zona believed then that the crisis had passed and headed home.

Upon returning to the hospital the following morning, relieved that their son survived, the doctor, who lacked a warm bedside manner, asked Ed's parents how they would like it if they had to spend the rest of their lives in an iron lung? Zona immediately became concerned this physician would convey a sense of hopelessness to Ed. Her fears were somewhat alleviated when the same doctor suggested putting a clock in Ed's bedroom so he would be aware of the time.

Some Sister Kenny methods were practiced at the hospital, including exceedingly painful hot packs. Hospital personnel moved Ed in and out of the iron lung and eventually out of isolation into a ward with other polios, as they call themselves, of all ages and both sexes.

A new routine settled over the family. Zona would visit Ed in the afternoons. Verne, whose role was to be in the hospital every evening, began to develop a nurturing side.

Verne had recently bought an insurance rider for 50 cents per month to cover polio for up to \$5,000. When Ed first entered the hospital, the family waited to find out if he had polio to know whether he would be covered by the newly-acquired policy. Zona was outraged at having to wait for a lab report to know whether he would become a public or private patient. Once the polio was identified, Ed became a private patient for two and a half months. Then the March of Dimes covered the

remainder of the hospital bills, while the family spent years paying off the doctors' bills.

Medical practitioners of the 1950s believed that polio survivors should do their utmost to become independent of an iron lung. For someone like Ed, whose level of paralysis meant his lungs no longer had the capacity to breathe on their own, that meant a terrifying fear of lack of air. Could he tolerate being out of the lung? Only time would answer that query. Ed naturally learned to frog-breathe, but was told to stop because of a belief that it was not helpful, he would not get more air, and it was looked upon with disfavor.

Ed remained hospitalized for the greater part of two years. This time was crucial to see how the swelling would go down and what nerve endings would be corrected. Beyond two years there was no hope for further recovery.

During the first year, Verne and Zona once left town for a week to visit friends at the Russian River, a popular northern California vacation spot. They received a healthy dose of criticism from other polio families. Zona, however, recalls she knew Ed could adapt to the polio when he handled that trip. She later learned from Ed that he thought that excursion abetted his recovery. The polio had caused enough pain in his life; if his parents sacrificed their lives it would be more than he could bear.

Ed remained at San Mateo County Hospital for about nine months. Although he recovered from the initial ravages of the disease, the hospital lacked a rehabilitation program to teach him how to live with the aftermath of polio. The family learned about such a program at Children's Hospital in San Francisco. Zona arranged to move Ed. On the day of the move, they got Ed and put him in the back of the station wagon to move him from one hospital to the other. Ed became furious for no apparent reason. All Zona could imagine was that Ed felt akin to a dog going to the pound, removed from familiar surroundings. For the first six hours or so Ed spoke to no one.

Zona had to learn to drive to visit Ed in San Francisco. She had started to learn once before, during World War II, but gas rationing prevented her from completing the lessons. This had not displeased Verne. Since he liked Zona at home, the freedom she would acquire from driving did not excite him. Zona had to plan how she would convince Verne that learning to drive and being able to visit Ed herself would be appropriate. This kind of strategic planning had become a part of Zona's life at which she was quite successful and it would be propitious not only for her, but for Ed's recovery and return to family and community life.

She finally got her license when Mark was two years old and began to attend the Co-op Nursery School. She enrolled in an adult driving course at San Mateo High School. Both Mark and then Randy attended. The school relied upon parent participation and each mother had to help teach one day a week, while both parents were required to help on work days. On the day parents taught, they drove the car pool and then had the other days free. Driving into San Francisco intimidated Zona at first. The Red Cross drove her to the hospital in San Mateo when Ed was first ill. Though it was difficult, Zona had to drive herself there and to arrange for Randy's care, taking him and the playpen and diapers and the other baby paraphernalia to whoever watched the two younger ones when she visited Ed.

While in the hospital, Ed did not eat well for a time. Speculation abounded about the cause, including frustration from being unable to feed himself. Zona attended a doctors meeting where she learned that with polio the hydrochloric acid of the stomach is almost depleted and digestion is difficult. But Ed's difficulty with eating was not totally physical.

Zona observed a private duty nurse pressuring Ed to eat. Zona's younger boys attended a co-op nursery school family car pool sponsored by College of San Mateo. A fellow parent and car pooler, psychiatrist Gene Gordon, recommended the private duty nurse be removed because this pressure was too intense and counter-productive. She was removed. Ed still had to be fed, but his attitude changed when the pressure was off. He later made many public declarations about his lack of desire to eat until he was left alone to make the decision to survive for himself.<sup>5</sup>

While Ed resided at San Mateo County Hospital a news story about the polio epidemic included a camera shot that panned over Ed while the newscaster described him as being unable to

move. Zona, watching the story, for the first time cried about her son's polio.

The hospital was filled with polios, many without families. Ed, with obvious support from home, began to think that life as a polio survivor could be okay.

Rehabilitation work occurred during the nine months that Ed spent at Children's Hospital. He would, for example, try to feed himself with a sling but it would take most of the day for one meal. As he adapted to his condition, being fed by someone else did not seem as restrictive when he could put his energies to alternative uses.

At the end of two years, Ed prepared to return home. The prospect terrified Zona. Distressed and depressed, she feared she would never be able to leave the house again. She had difficulty sleeping. She believed she needed someone to discuss matters with, but found it difficult to do so. Friends advised her to call a social work agency. When she called the San Mateo Social Services Agency she was sweating so much the phone fell out of her hands. She began to meet with a social worker, a wonderful woman. Verne went once, but did not return.

One day at the hospital, a social worker dropped by and commented about how excited Zona must be to have Ed returning home. Zona admitted she was terrified and the social worker expressed surprise and asked if anyone had spoken with her about the Polio Foundation, which provided and paid for assistance to families four hours per day five days a week. They had not. The pair left the room and Zona learned she could hire an assistant with the help of the Foundation. This enabled Zona to feel more confident about the many changes to come. She interviewed and hired Mrs. Hibner, another wonderful woman.

First and foremost, the house that the Roberts family lived in across from the high school was no longer adequate. It was not big enough to accommodate Ed's iron lung and associated paraphernalia. The family moved to another house where a bed was set up for Ed in the dining room. With Ed's arrival from the hospital to the Roberts' new home a fresh routine began.

## Post-polio

The effects of the polio virus remained throughout Ed's lifetime. He retained some movement of two fingers on his left hand and two toes on his left foot. The rest of his body, including his lungs, remained paralyzed. Unable to breathe on his own for extended periods, he became, in the language of the day, a ventilator-dependent quadriplegic. This meant that both his arms and legs were paralyzed and that he required a machine, such as an iron lung or a ventilator, to assist him with breathing. Although he could not move, feeling remained.

Ed spent two years attempting to breathe without the iron lung, but it was a losing proposition. While Ed was in San Mateo County Hospital and then at Children's Hospital, he used a rocking bed that was designed to work by rocking the person lying in it and pushing air from the stomach to the lungs, but this did not work for Ed because he was too skinny. He was then introduced to a cuirass - a shell that fitted over his chest with a hose that attached to a machine pushing air into the shell. He came home from Children's with that chest respirator. Although he continued to breathe on his own, despite the doctors discouragement, "frog-breathing" required an enormous expenditure of energy.

A slew of immediate, medical problems plagued Ed after his return home. In one instance, he became lethargic in the afternoons at the same time that he had big blotches on his face. Zona heard about Fairmont Hospital, across the San Francisco Bay in San Leandro, described as equivalent to Southern California's highly respected Rancho Los Amigos, the polio rehabilitation center that had pioneered home care for former patients. Funded by the March of Dimes, they were responsive to Zona's call. She believes that getting Ed there saved his life again. He stayed at Fairmont on two occasions, for about two weeks to a month each time. During his first stay, doctors performed a cardiac catheterization to determine if there had been heart damage as a result of not getting enough oxygen and discovered the left side of the heart did have some damage. That had caused the blotches.

On the second visit, Zona believes he went into shock from a kidney stone, and Leon Lewis, a physician who included Zona in discussions about Ed's treatment, suggested Ed return to the iron lung. This had been discussed when the oxygen deficiency was discovered, but not acted upon. After

the kidney stone episode using the iron lung became mandatory because he was not getting enough air from the chest respirator. After all this time of trying not to use the iron lung, Ed thought he had failed, but once he was in it he became comfortable in minutes. He never regretted this decision. He felt most comfortable in this cocoon where he was not required to concentrate on breathing, but could focus his attention on other matters. The lung became a lifelong friend. He would enter the lung during the evening. Once daytime returned, he would leave the lung behind, either breathing on his own or using a ventilator.

Verne's mechanical and electrical ability made life easier for the family. He also had a knack to be able to awaken in the middle of the night, fix or repair whatever needed it, and go back to sleep.

The Roberts' post-polio routine included Verne arising early to go to work, Mrs. Hibner arriving to provide assistance, Verne returning in the afternoon, and Zona serving dinner about 5:00. Verne often had soda crackers, coffee, or beer before dinner. This was also the time when Ed would be bathed. Verne would support his head and neck, Zona his butt and knees. Ed's immobility had immediate consequences even in the sanctity of home. For example, once in a while during dinner, the family's pet cat, Tigre, would be allowed to be present and to the great amusement of all would lay by Ed's head and steal meat from Ed's fork before he could get to it.

Ed, the only person in his school to contract polio, resumed his education at Burlingame High School at the age of eighteen. He joined brother Ron's class of sixteen year-olds, attending via a phone hook-up promoted by the phone company and provided by the San Mateo County Women's Club. It began with a phone connected to one room at the high school. When Ed pressed a bar on the phone he could be heard, when he released the bar he could hear, enabling him not only to listen but to communicate with his classmates. Hands-on tutoring was provided for Spanish and biology courses.

The phone hook-up also began what would become a lifetime of publicity about Ed. His picture and a short write-up appeared in the phone bill.

Zona thought she paid attention to her other three boys during these years, but remembers Ron getting caught stealing and stating that he was feeling neglected. About this time he started playing basketball and tennis at the high school and the family bought him a membership at the tennis club. Ron became co-captain of the high school tennis team and also played basketball. He did not date or drink, but played poker. The two younger boys, Mark and Randy, attended Washington Elementary School.

The entire family played a role in Ed's care. All would pick up dropped items or turn the television on and off and numerous other tasks. Mark and Randy both would help out as Ed's attendants at various times after Verne died and Ed moved to Berkeley. Both also earned money later as students by providing personal assistance.

Verne continued to like routine, including wanting to know the whereabouts of all his family members. He loved fishing (but not eating what he caught); liked barbecuing in their back yard, playing bridge, and generally being at home. He and Zona seldom went out together, but they often entertained together, hosting people for dinner and bridge.

Zona still had her own dreams. Two things she always wanted to do were travel and go to college. At this juncture she did not believe she would get to do either.

During his senior year, Ed sometimes went to sports events and wrote a sports column for the Burlingame Bee. He read with a book or magazine on an elevated bed tray and using a mouthstick so he could turn pages without assistance. He listened to the constant bustle of his busy home. He watched TV. Many visitors would come into Ed's open area in the middle of the house. Since he could not escape, he learned how to tune out and fall asleep as a way of escaping people's problems, which became a lifelong habit.

Once a semester Ed's class met at his house. During Ed's senior year Zona informed him he had to attend classes once a week at the high school. Ed was terrified; he had not associated with students since he had left the community as a star athlete in eighth grade. He was returning a cripple. His greatest fear was that he would be stared at. He was. His eventual response to being on exhibition became if everyone was going to be looking at him anyway he would be a star. But it was awhile



before Ed would let people see him in public. Once when Ed was about nineteen and Mark pushed him along Burlingame Avenue, a man stopped to ask Ed what was wrong with him. Ed could not answer. At this juncture, he had no desire to be around other people with disabilities, not wanting to be identified as one of them.

Ed had wanted to be a Marine. He was an avid gun collector who persuaded Zona take him to gun shops. Ed even took a terrified Zona to rifle ranges where he would direct her in how to shoot. This and sports kept him in touch with the guys.

Ed graduated from high school, at the age of twenty, in 1959. But not without a fight. His post-polio paralysis prevented him from taking either physical education or driver's education courses. His high school counselor thought Ed should remain in school another year. Zona, determined that her boy would be as similar to his peers as possible and having done all in her power to achieve this end was mystified by this turn of events.

Zona contacted the principal about the inequity of the situation. He supported his counselor. Zona next called her friend, Mimi Haas, the mother of one of Ron's friends and a school board member, to see what could be done. A school representative met with Zona and Ed at their home and asked, "Ed, you wouldn't like a cheap diploma, would you?"<sup>6</sup> A furious Zona got in touch with the Superintendent of Schools, whom she knew from PTA work. She also called some of Ed's teachers. They planned to advocate for his graduation at a school board meeting. Before they could act, the Assistant Superintendent of Schools announced that everyone was proud of Ed and granted the diploma.

At the graduation ceremony a fellow student pushed Ed across the stage. A big party followed at the Roberts' home. Ed later commented that he attained some of his own sense of determination from watching Zona persevere about his graduation.

Ed and Ron graduated at the same time. Ron ventured across the bay to attend the University of California at Berkeley. Ed enrolled at the nearby community College of San Mateo. To attend classes he was placed in a corset, which enabled him to sit up. A head brace came out of the back of the corset.

At first, Zona brought Ed to campus. They would solicit help from passers-by to get Ed in and out of the car on campus, learning to avoid the football player types who wanted to do it all by themselves without consideration of Ed's needs. Once at the college, Ed attended class by himself, with assistance from fellow students, to traverse the numerous steps. A fellow student was eventually hired to drive Ed back and forth to campus.

Ed spent three years at the College of San Mateo finishing two years of class work. To complete assignments Zona wrote while Ed dictated. Ed speculated about a career as a sportswriter. Others discussed technical writing. He eventually chose political science as a major.

Ed earned no money either in high school or at the College of San Mateo. Zona thought the California Department of Rehabilitation (DR) might pay for some books and began an interaction with that agency that would eventually prove to be a watershed relationship for people with disabilities throughout the country. But that was still to come.

The most fortuitous development at the College of San Mateo for both Ed and Zona occurred when Ed enrolled in an English class taught by Jean Wirth in his second semester. Jean, like Ed, knew about difference. She had been six feet, five inches tall from the time she was twelve years old. She became his unofficial advisor after his class with her.

Jean asked Ed where he wanted to continue his education after graduating from the College of San Mateo and he responded the University of California at Los Angeles (UCLA), because it had a program for veterans which he speculated would make it fairly wheelchair-accessible. Zona was surprised, since he had never discussed this with her. Jean dissuaded him from this idea because UCLA was a commuter campus and he would have to find housing, transportation, personal assistance, and friends away from the university. She suggested instead that he apply to the University of California at Berkeley (UCB) where there was an outstanding political science program.

Ed did just that and was accepted at UCB. The application form asked no questions that

related to disability. The only hint was that Ed weighed only eighty-five or ninety pounds. Zona accurately predicted that school officials would guess Ed forgot to put a "1" before the other numerals.

Ed also applied to DR for financial assistance. The DR counselor informed Ed that he was too severely crippled to work and would therefore be denied services. Zona, Jean, and Phil Morse, Ed's official advisor at the College of San Mateo, then met with DR to advocate successfully for Ed.

While this was happening Jean, Zona, Ed, and Phil visited the UCB campus prior to the commencement of the school year. UCB personnel were shocked to learn that Ed was a post-polio ventilator-using quadriplegic and were at a loss about where he might be housed. His large iron lung would not fit in a dorm room. Morse contacted the Dean of Men, who suggested they see Henry Bruyn at Cowell Hospital, the on-campus student health center.

Bruyn, a physician, had worked with polios and commented that they were coming of college age and should be able to attend colleges. He thought Ed could probably live at Cowell. Successful negotiations to do just that continued throughout the summer.

### **East and West of the San Francisco Bay**

EAST - ED ROBERTS: Zona stayed with Ed during his first week at UCB, while both interviewed personal assistants. She then returned home and came back to Berkeley about one month later to see how Ed was managing. Ed would remain at Berkeley throughout most of the 1960s, but Zona had little to do with his life there. Just as she felt her role as Ed's mother demanded that she be present at earlier crises, like the onset of polio and the potential fiasco surrounding Ed's timely high school graduation, she realized the time had come to let Ed make his own way into the world and to return to her own life. A brief highlighting of Ed's impact while a student at Berkeley demonstrates how well Zona and the rest of Ed's circle of support succeeded in conveying to Ed a sense of power that augmented his own natural capabilities.

During Ed's first academic year, 1962-63, the same year that James Meredith integrated the University of Mississippi, he was the only student with a disability at Cowell, and, as far as we know, the first student with a disability of this significance to attend an American university. An area paper ran a story about Ed headlined, "Helpless Cripple Goes to School."<sup>7</sup> It caught the attention of a social worker in nearby Antioch whose client, John Hessler, had broken his neck while diving. Towering above six feet tall he was too big to be cared for by his parents and he lived in a Contra Costa hospital. He attended Contra Costa College, going back and forth by taxi. His social worker spoke with Henry Bruyn, after reading the newspaper story, and John joined Ed at Cowell in the 1963-64 school year. He majored in French language and literature.

Bruyn began to garner a reputation for this program. Several more students arrived in 1965-66. Their arrival signaled a formal program for students with disabilities, who started to call themselves the Rolling Quads.<sup>8</sup> They were moved from the second floor to take over the entire third floor, with a nursing supervisor. Each student had his or her own room. There was a common room and a dining room where the Rolling Quads met together. Ed and John roomed next to one another on the second floor. They stored beer in the shower.

Once Ed attended a basketball game, watching from the gymnasium floor, the only spot accessible to him, and a player stepped on his foot. On the way home, he stopped at a bar to get a drink and obliterate some of the pain. After awhile he needed to urinate, but could not use the bar's inaccessible bathroom, so he was given a beer pitcher to take into the bushes near the bar. Apparently, others had used the bushes for the same reason and peeved neighbors called the police. They were going to arrest Ed and he mischievously encouraged them, knowing that they had no way to get him there or keep him in jail. They finally decided to let him go. Ed expressed delight to be perceived for once as a bad boy.

Ed's DR worker in Berkeley, Katherine Butcher, unlike his geographically appointed counselor in Burlingame, was supportive of his efforts and DR paid for tuition, books, and secretarial help. Toward the end of the 1960s, a radical change occurred when DR installed a new worker who be-

lieved she should dictate behavior. She attempted to direct Ed's thesis topic and tried to instruct other students in what classes they could take. She also tried to get two students evicted because she felt their educational goals and lifestyles were inappropriate.

The students responded in several ways. The Rolling Quads formally organized themselves into a student organization and as such they developed and taught a university studies class called, "Strategies of Independent Living," whose main purpose was to conceive methods to live outside of Cowell. They brought their frustration with their new DR worker to the press and succeeded in getting her transferred. Then they began to talk to the Berkeley City Council about building ramps in the city. The Rolling Quads were not only testing their limits as fledgling citizens, they were also beginning to understand their own power in ways that would eventually be an integral part of changing the way all Americans perceived individuals with disabilities.<sup>9</sup>

**WEST - ZONA ROBERTS:** Zona's own desire to be active away from home intensified with Ed and Ron at college across the Bay. While Ed studied at Berkeley, Zona benefitted from her own friendship with Jean Wirth. It had begun one day when Zona took Ed to Jean's class at the College of San Mateo. While there Jean told Zona she knew she would like her from her handwriting style. A lifelong friendship began.

While Zona eagerly explored activities outside the home, Verne Roberts expressed frustration when Ed left for UCB. Everything in their house for years had revolved around their dining room where Ed lived. Verne was uncomfortable with the change.

Always strong and athletic, Verne began to feel lethargic during the summer of 1963. Physicians first believed he had pleurisy, a serious respiratory condition necessitating a lengthy recovery period. Verne was directed to rest and not work. Months later, after New Year's, still feeling poorly, he went to the hospital. A biopsy now discovered that Verne, a smoker, had lung cancer that had metastasized throughout his body.

Shortly thereafter, Verne was hospitalized and doctors informed Zona that he would soon die. Verne refused to acknowledge his condition, refusing to draw up a will. He even got angry when Zona visited. He thought she should be at home. Once she visited him with Jean Wirth and Mark, who was now twelve. Verne was asleep when they got there and when he awoke Mark was crying. Verne looked at Zona and asked why she had hit him?

The cancer eventually spread to Verne's brain and he died around Valentine's Day in February 1964. He was forty-seven years old. Verne and Zona had been married for twenty-seven years.

Within a month of Verne's death, Zona started attending the College of San Mateo. Since two of her kids were still under eighteen, Social Security for Survivors made it possible for her to attend school. Jean Wirth supervised her selection of classes.

Jean had relinquished her teaching job to start a college readiness program and asked Zona to assist in its implementation. Thirty-nine Black students became the program's first cohort. Each student had a tutor as well as access to a tutoring center. Thirty-seven of the students stayed in the program and the almost total retention rate caught the attention of folks in Washington, D.C.

The college-readiness program that Jean supervised eventually attracted many more students. Black students began to be replaced by Chicanos, who tended to be more aggressive than their predecessors and they frightened the administration. As a result, Jean was fired. She tried to return to teaching, but no longer found it satisfying and quit. About that time she received a call from Washington, D.C., specifically because of the retention rate of students at her program, asking her to work for the Department of Health, Education and Welfare (HEW). She moved to the nation's capital. This career change would eventually impact both Zona and Ed.

Zona was finishing at the College of San Mateo and applying to continue her education at Berkeley and San Francisco State University. She was accepted at both schools. Tired of Burlingame's restrictiveness and conservatism, where Mark had been yelled at for having a Beatles haircut, and racial prejudice thrived, she began to consider moving. Burlingame High School included only one black student, the son of a diplomat. More worrisome, Zona often had black students from the College of San Mateo staying at her house causing great consternation in the neighborhood. She feared what

might happen. At the age of forty-seven, Zona decided to make another big change in her life and moved across the Bay, arriving in Berkeley in 1967.

## Berkeley

Zona loved Berkeley. She thought she was the proudest student on campus. She experienced the rebellions at UCB throughout the 1960s. Many decisions had to be considered about attending classes with the tear gassing and shootings on the street.

Her new house in Berkeley on Ward Street became affectionately labeled the "green house" for its outside paint job. The family's house in Burlingame sold for \$19,000 and the house in Berkeley cost \$59,000. Like her house in Burlingame there were always people there, including Ed, who would visit periodically.

When Zona earned her B.A. in 1969, her sons got together and gave her a graduation present of a trip to Europe for three months. Mark traveled with Zona. They began in Rotterdam and journeyed to Paris and Heidelberg, took a seven-day Black Forest tour on big Nort, a Norton motor-bike, then on to Bologna, Rome, Venice, and Paris before returning to Rotterdam and home.

At the age of forty-nine, Zona's dreams, that only a decade ago had seemed unreachable, had come true. She had gotten an education and she had traveled. When she returned from Europe, she returned to UCB for one more year. She acquired her teaching certificate in 1970.

Zona thrived in Berkeley, but by the late 1960s Ed tired of being there. He had completed both undergraduate and graduate school, finishing all but his dissertation. Ed heard about a temporary job at the Disabled Student Services program in Riverside, in southern California. He planned to fill the position.

Before Ed left, Jean Wirth called Zona from Washington to share information about a bill providing quite a lot of money for disadvantaged students, with ten percent of the budget earmarked for disability programs. Jean suggested Zona come to Washington for meetings about how to utilize the money, but Zona who had a scheduling conflict recommended Jean call Ed.

Ed was agreeable and made the heady decision to travel by airplane away from the comforts and necessities of home for the first time. Mark went with him as his personal care attendant (PCA). Ed experienced the first of many adventures traveling as an individual with a disability. First, no breathing apparatus was allowed on the plane, so Ed was forced to do his exhausting frog-breathing for hours in the air. Then upon landing he sat for more hours while they retrieved his manual wheelchair. Jean arrived at the hotel before Ed to arrange for an iron lung to be delivered to the hotel. She learned that an iron lung would not be allowed because "they blow up you know." Ed knew he would stay somewhere else than the rest of the conference participants, which did not please him. It was another taste of discrimination.

Despite the hardships, Ed loved Washington. He reveled in interacting with Senators and Secretaries, and with time's passage would realize that he too had made a lasting impression.

Since Ed was on his way to his temporary job in Riverside he urged John Hessler and others to submit a proposal to HEW for funds to institutionalize what they had learned as the Rolling Quads. Their first attempt did not get funded, but their second one did. It became the Physically Disabled Students Program (PDSP).

John Hessler became Director of the program. Zona began working half-time at PDSP while seeking a teaching job. PDSP provided transportation and personal assistance in the home. The first group of PCAs came from all over the United States. Some were conscientious objectors. At PDSP, Zona both drove people to and from campus and rescued people needing personal assistance. She was on call night and day. She eventually managed the PCA services until leaving to pursue her Master's degree.

Ed, meanwhile, did not remain in Riverside long. His physician advised him to leave because the area was harmful to people with breathing problems. He then moved to Woodside in the South San Francisco Bay area and began teaching at Nairobi College in East Palo Alto. The college attracted less traditional students than those attending UCB or nearby Stanford. Jean Wirth had also

returned to the area from her sojourn in Washington and started Common College in Woodside. Ed taught there as well, but left in the early 1970s to return to Berkeley.

The program that Ed had suggested and others had implemented, PDSP, began to attract individuals with disabilities from around the San Francisco area. Many callers were not students, but there was nowhere else they could obtain the services they needed. The need to create an organization similar to PDSP for non-students became apparent.

Three people, all of whom had been Rolling Quads, began an organization they called the Center for Independent Living (CIL). A small Research and Development grant enabled them to rent a small apartment and begin CIL. John Hessler was a board member who became concerned very quickly that the much-needed CIL was failing because of a lack of leadership. He spoke with Ed after the latter returned from Woodside about his fears. They agreed something needed to be done.

Ed and John met with their friends and discussed a Board take-over. Their strategy succeeded. After that happened Ed became CIL director because he did not have a job while Hessler directed PDSP.

Ed found an office building with space to rent on University Avenue, with second floor offices and an elevator. It was outfitting these spaces for people with differing disabilities that caused him to go to Fairmont Hospital and talk to therapists there to see what types of equipment would work for his staff. There he met Catherine Dugan, an occupational therapist, whom he later married.

CIL moved soon to an old car dealership on Telegraph Avenue, near campus. Ed convinced former Berkeley radicals to run a machine shop/van shop on the premises. CIL had to have a transportation system because people could not get around without it. Ed expanded CIL rapidly and a national, then international, reputation quickly followed.

When Jerry Brown was elected governor of California in 1974, three of his former law school classmates, who happened also to be friends of Ed's, nominated Ed to become Director of the Department of Rehabilitation (DR), the agency that had once told him he was "too severely crippled" to ever work. Brown interviewed Ed and did appoint him to become DR Director.

Ed brought John Hessler to Sacramento as his Assistant Director. Hessler did not remain happy in this position after he had been running the show for so many years. He eventually went to the Department of Health where he remained until he died.

Ed and Cathy married in the back yard of their Sacramento home. Cathy gave birth to a son, Lee Roberts, in 1978. The delivery occurred at home so Ed could participate. He called Zona after the baby was born and said, "bet you didn't think I'd be the first one to give you a grandchild." Zona responded, "You're absolutely right."<sup>10</sup>

The marriage lasted only a few years. Ed retained joint custody and brought Lee with him on his travels from an early age. Toward the end of his life, when people from all over the world asked Ed what he liked to be called he usually replied "dad."<sup>11</sup>

### Coming into Her Own

When John Hessler resigned from PDSP to move to Sacramento with Ed, Zona was offered the Director's position. She declined. She felt a person with a disability should run the program. She also lacked interest in that particular position and sought other professional possibilities. As it turned out, Zona did not mesh well with Hessler's successor. At the age of fifty-five, Zona resigned.

Just before Zona left PDSP she heard about family therapy. A friend gave her a ticket to a program about it at the University of California at San Francisco and Zona loved what she heard. The Family Therapy Institute of San Francisco offered a beginning course in Berkeley which she entered.

Zona applied to the Berkeley School of Social Welfare after quitting PDSP. The School rejected her because she had a job and was older. She also applied and was accepted at the John F. Kennedy School (JFK) in nearby Orinda, northeast of Berkeley, which encouraged older students. She could attend JFK on evenings and weekends. She completed all her work but her thesis. She then applied to the Wright Institute, also in the area, to work toward a doctorate, but decided against it because of the cost.

Zona did not know what would come next. She had a small pension of \$100 per month and health insurance. She had sold the "green house" to the same people from whom she purchased it and moved to Oakland. She had been ready to leave her formerly beloved neighborhood because the area was changing - as older people died, landlords bought their homes and turned them into apartments, altering the mood of the neighborhood and crowding it.

CIL called Zona during this transition. Peter Leech had started a counseling program in CIL's early days and he would call Zona at PDSP to meet with parents and attend peer counseling strategy courses Peter set up. Zona also volunteered at CIL, doing family therapy and was eventually hired by Hal Kirshbaum while she worked on her Master's degree.

Watching Ed and his peers over the years speak at school assemblies and other venues, Zona observed the power not only of their presentations but of their presence. Simply seeing someone like Ed out and about in the world had a profound effect upon children and teenagers with disabilities and their families who had never seen anyone with significant disabilities in an active role and who therefore had no previous role models upon which to base their future.

Knowing how potent these appearances had become Zona realized that she too was a peer. She became especially adept at working with parents of disabled individuals. She could ask hard questions, like what kinds of plans did parents have for their children to move out and live independently on their own, and did they still keep time for their own lives, including sexual activities, and she could share her own experiences. She became a sought-after worker and speaker.

Tragedy struck one Saturday night in 1981. Zona's youngest son Randy was murdered. Remembered as sweet and sensitive, Randy drove a van for CIL, made exquisite chocolate truffles, and sold marijuana. On the night of the killing, Randy let someone in the house, ostensibly to make a buy, while entertaining a woman friend. The little that is known about the murder comes from the friend. She related that the man Randy asked in said, "give me your bag or I'll kill you." Randy replied, "guess you'll have to kill me." Randy's woman friend emerged from the kitchen to see what the commotion was all about and Randy stepped in front of her to block her from harm and then took second shot in the heart that killed him instantly. The case has never been solved and remains open.<sup>12</sup>

When the police informed Zona about her son's murder she was living alone in Oakland and they would not leave until she called a friend. A few hours after Randy's death the house was filled with people, food, and wine. At the memorial service at CIL Zona received many condolences about her gentle son. A small ceremony was also held at Tilden Park in Berkeley after a cremation.

Zona left CIL in 1982. Some families with whom she had been working wanted to continue seeing her. She started a small private practice, calling herself a Family Disability Counselor. She chose clients carefully. They are people who are not in great difficulty, but need supportive counseling. All come via word-of-mouth. Zona was particularly supportive to women who are facing the same kinds of obstacles she once encountered as an abused child and as the wife of a man who did not want her to leave the house.

## Two Lives - Two Homes

Still in Sacramento and wondering what he would do after Jerry Brown's terms as governor were completed, Ed and two of his colleagues planned an organization called the World Institute on Disability (WID). Ed remained in Sacramento, trying to sell his house there, while WID began in Berkeley in 1983. This was a difficult time for him. It was not easy to find PCAs in Sacramento and now that he was no longer in state government he felt that Berkeley was where the action was. He finally decided to return to Berkeley to join WID prior to the sale of his house.

Zona asked Ed if he wanted to move in with her since she was alone and he was surviving on Social Security benefits because he no longer had a job. He moved into the living room once more.

Ed did not depend on Social Security for long. Within a year of his return to the Bay Area he received a call from the MacArthur Foundation, asking if he would be willing to accept what is commonly known as the "genius" fellowship, a five year award that is designed to enable people of great vision to pursue their dreams without money worries. Part of the monetary award went to a

university or a program of the recipient's choice. Ed used it as seed money for WID.

The first WID project (a place Zona never officially worked) concerned learning about the different kinds of personal assistance programs throughout the country. In fifteen years WID's expansion has been rapid and involves many projects, but the initial project remains an ongoing one.

After a few years, Zona began to chafe from her lack of privacy at home. Ed and his PCAs had taken over the downstairs. Zona could not entertain like she had before Ed moved in. They had plans drawn up to expand the house, but the cost came in at \$90,000, in the California real estate market that had skyrocketed in costs since Zona had first moved to Berkeley. Zona suggested Ed look for a place to live since he had finally sold his Sacramento house, but he did not have the money for a down payment.

They decided to look for another place together and found a house in Berkeley. It had a back apartment known as an "in-law unit" built twenty years previously. Zona provided the down payment and Ed paid the mortgage on the new house on Eton Street in Berkeley. They moved there in 1991. Zona continued with her practice, traveling when she could to visit friends and family and when she had the opportunity to other international destinations. In the continuing irony of the man who was told by DR that he could never hold a job, Zona traveled with Ed twice to France and once to Japan after Ed received government invitations to participate in international rehabilitation meetings. Ed continued his stewardship as President of WID and became an international traveler who garnered a worldwide reputation as the father of the modern disability rights movement.

On a March morning in 1995 Ed died from a heart attack or blood clot while Zona was visiting Ron and his family in Hawaii. Ed had just finished breakfast. Jonathan, his PCA, held up a pair of pants and asked Ed if those were the ones he wanted for the day. Ed dropped his mouthstick in an unusual way. By the time Jonathan got to him he was dead. There was no autopsy.

When Zona learned about her son's death, she immediately returned to Berkeley and opened up their house to their family and friends. Their home was filled with people, food, and memories. Within a few days a memorial service was held. So many people were expected that it was held at Harmon gymnasium on the UCB campus. Obituaries from all over the world recalled Ed's life and impact. Few mentioned Zona except as his surviving parent.

## Legacies

Legacies from the lives of Zona and Ed Roberts abound. Just as the breaking of the color barrier at American universities in the 1960s led to nationwide integrated campuses, Ed's attendance at UCB has paved the way for thousands, if not millions of others. In 1974, Congress passed the Education of All Handicapped Children Act guaranteeing an equal education for all children with disabilities. College campuses across the world are now implementing disability studies programs.

PDSP was the first program of its kind. Now almost every university and community college has a similar program, no longer restricted to students with physical disabilities.

CIL was the first organization of its kind. There are now more than three to four hundred in the United States and many more across the world.

Ed became the first person with a disability of his significance to direct a state Vocational Rehabilitation agency. Many more have followed in his wheel path.

WID has grown from its beginnings of three people in 1983 to an organization of dozens of employees known throughout the world for a multitude of activities.

The MacArthur Fellowship has been awarded to other disability rights activists since Ed received one in 1984.

Ed's legacy may live on most fundamentally in the individuals he touched. At a memorial service held at WID shortly after Ed's death, a woman related the story of how her parents had moved to the United States from the Far East after she became disabled. She ended up in a hospital in the Bay Area wishing she were dead. When asked if she wanted anything she made a request to meet Ed. He visited. While there she related her story and he began to cry. When she saw his tears that he could not wipe from his face she realized that she possessed physical capabilities that he did not. Yet he was a

powerful, happy man in his huge, electronically powered wheelchair, breathing with the aid of a respirator. She wondered why she was lying in a hospital bed. She got up. She has since become a well-known artist in the Bay Area.<sup>13</sup>

Her story is one of hundreds, if not more, of the people Ed touched directly. Many more got out of their beds, or their nursing homes, or their lives of listlessness, after hearing Ed speak or seeing him on television or reading about him in the press.

Ed changed Zona's life in fundamental ways. She reminisced that she learned from Ed about inclusiveness, disability, connections, world-wide experiences, and being brazen. She also became aware of the importance of noticing and accepting differences. For instance, if someone does not notice a wheelchair the possibility of being run over by it is much greater than if someone pays attention.

Zona had both a mother's and a pioneer's impact on Ed. Aside from the remarkable life he lived, Zona believes Ed gained from her knowledge and compassion about love and loving. I believe he also gained a lust for life which he, like his mother, demonstrated for all the world to see.

Zona continues to live in Oakland. She rents the "in-law" unit as well as rooms in the front of her house. Ron and Mark are both alive and well. Zona has six grandchildren. She has been a visible presence in each of their lives. Her desire and success in creating in her own family a stability unknown to her as a child remains her most important personal legacy. That she was able to achieve it in the face of Ed's bout with polio and its aftermath helped to give the world a human rights legacy.

My hopes are that the stories of parents who have been pioneers, like Zona Roberts, will become an everyday part of our history; that Ed's breaking of the educational barriers at an American university will be told in the same paragraph in the same textbooks with that of James Meredith, his historic counterpart; and that the struggles and accomplishments of the disability rights movement will take their rightful places in our national storytelling alongside those of the civil rights, women's rights, gay and lesbian rights, and other minority rights movements of our country's illustrious, but not always so magnificent history.

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## Endnotes

1. A fuller description of this experience is found in Steven E. Brown, *Investigating a Culture of Disability: Final Report* (Las Cruces, NM: 1994), 69-70.
2. Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: 1993), 56.
3. Zona Roberts interview by Steven E. Brown, Dec. 27-30, 1996, audiotapes (in Steven E. Brown's possession).
4. Roberts interview, side 2, tape 2.
5. Mr. Roberts. (circa 1988). Sixty Minutes. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612).
6. Roberts interview, side 2, tape 4.
7. Shapiro, *No Pity*, 45.
8. Brown, *Investigating a Culture of Disability*, 50-51, Steven E. Brown, *Independent Living: Theory and Practice* (Las Cruces, NM: 1994), 28-30, Shapiro, *No Pity*, 47-55.
9. Hale Zukas. "CIL History," presented at Independent Living Conference, October 21-23, 1975, Berkeley, CA. (in Steven E. Brown's possession).
10. Roberts interview, side 2, tape 6.
11. Ed Roberts interview by Steven E. Brown, Sept. 8, 1993, audiotape, side 2, tape 1 (in Steven E. Brown's possession).
12. Zona speculates that the murderer himself is probably long dead. Roberts interview, side 1, tape 7. In another conversation about the murder, Randy was described as stepping between



the girl and the gunman, who was aiming at his date. Lillian Gonzales Brown, personal communication, Aug. 15, 1997.

13. This story was related at a small memorial service for Ed held at WID on March 20, 1995 which I attended.